Expanding Access through Hospice Insights

CONNECT to Care

National Alliance
for Care at Home

Introduction

The Medicare hospice benefit was established in 1982 to cover services for patients who have received a prognosis of six months or less to live and provide much-needed support to their families. This benefit supports any hospice-eligible patient without limitation. On average in recent years, 1.7 million individuals utilize the Medicare hospice benefit annually, yet significant disparities exist in hospice utilization among certain populations.

The National Alliance for Care at Home (the Alliance) is committed to increasing access to care for all throughout the United States. By better understanding hospice care through the lens of access and inclusion, we hope to break down barriers preventing patients and families from receiving the support they need and desire. Recognizing that underserved populations extend beyond gender, race, or religion, members of the Alliance's Diversity, Access, and Health Disparities Workgroup sought to explore the unique challenges faced by those from historically marginalized communities, including rural populations. By examining gaps in hospice care and advocating for tailored services, we aim to foster more effective solutions for all.

Background

This research focuses on five key populations within the United States: African American/Black, Hispanic/Latino, LGBTQ+, Asian American, and Rural communities. Through knowledge sharing, data collection, and collaborative discussion, we hope to inspire stronger community partnerships, enhance education, and deepen the understanding of patient and community needs at the end of life.

We are proud to partner with Transcend Strategy Group on this important initiative.

This report brings together insights from multiple studies, including *Hospice Through the DEI Lens, Rural American Hospice Insights, and Exploring the Needs of the Asian Population*.

Identifying the Problem

Ongoing health inequities continue to impact Asian American, Black, Hispanic, LGBTQ+, and rural communities, including disparities in hospice utilization among patients from these underserved groups.

Defining the Goals

Gain deeper insights into the beliefs, attitudes, and lived experiences of communities who have been historically marginalized with regard to hospice and palliative care. Use these insights to close gaps in access and increase utilization of hospice care among all groups.

Setting the Strategy

The Alliance, in partnership with Transcend Strategy Group, conducted nationwide surveys (n=2,000) of adults (21+) who experienced the death of a loved one or have been involved with healthcare/life care (HC/LC) decisions for someone with a serious illness within the past three to four years. Participants identified as:

Black (n=400)	**Hispanic/Latino** (n=400)	**Rural** (n=400)
LGBTQ+ (n=400)	**Asian American** (n=400)	**Total** (n=2000)

** The survey was only offered in English, which may have limited accessibility by non-native English speakers.*

Respondents spanned a diverse cross-section of age, income, education, and ethnicity. This underscores the intersectional nature of their lived experience, with geography/rural identity being one of several factors influencing their needs and beliefs.

- **Intersectionality is defined as:** The understanding that human experience is jointly shaped by multiple social positions (e.g. race, gender, socioeconomic status) and cannot be adequately defined by considering social positions independently.

Total Respondent Profile (n=2000)

GENDER:	**AGE:***	**INCOME:**	**EXPERIENCE WITH:**
• Male: 880 • Female: 1048 • Trans: 24 • Non-binary: 36 • Other: 12	• 21-29: 216 • 30s: 288 • 40s: 216 • 50s: 192 • 60+: 300 • Asian and Rural ▪ <35: 324 ▪ 35-44: 236 ▪ 45-54: 144 ▪ 55+: 96	• Under 25K: 352 • 25K-50K: 496 • 50,001-75K: 368 • 75,001 – 100K: 308 • Over 100K: 408 • Prefer Not to Answer: 32	• Death of Loved One: 1696 • HC/LC Decision-Making: 1152

Note: *The Hospice Through the DEI Lens reported age by decades (20s, 30s, etc.) while the Asian Americans and Rural insights reported age by groups (35-44, 45-54, etc.)*

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AA/Black Demographic Profile (n=400)

GENDER:	**AGE:**	**INCOME:**	**EXPERIENCE WITH:**
• Male: 168 • Female: 232	• 21-29: 68 • 30s: 92 • 40s: 72 • 50s: 60 • 60+: 108	• Under 25K: 92 • 25K-50K: 112 • 50,001 – 75K: 88 • 75,001 – 100K: 36 • Over 100K: 60 • Not reported: 12	• Death of Loved One: 384 • HC/LC Decision-Making: 200

Hispanic/Latino Demographic Profile (n=400)

GENDER:	**AGE:**	**INCOME:**	**EXPERIENCE WITH:**
• Male: 176 • Female: 220	• 21-29: 84 • 30s: 96 • 40s: 76 • 50s: 80 • 60+: 68	• Under 25K: 76 • 25k-50K: 112 • 50,001 – 75K: 84 • 75,001 – 100K: 64 • Over 100K: 52 • Not Reported: 12	• Death of Loved One: 372 • HC/LC Decision-Making: 216

LGBTQ+ Demographic Profile (n=400)

GENDER:	**AGE:**	**INCOME:**	**EXPERIENCE WITH:**
• Male: 204 • Female: 176 • Other: 20	• 21-29: 84 • 30s: 96 • 40s: 76 • 50s: 56 • 60+: 92	• Under 25K: 92 • 25k-50K: 124 • 50,001 – 75K: 64 • 75,001 – 100K: 60 • Over 100K: 56	• Death of Loved One: 368 • HC/LC Decision-Making: 232

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Asian American Demographic Profile (n=400)

GENDER:	AGE:	INCOME:	EXPERIENCE WITH:
• Male: 168 • Female: 172 • Trans: 24* • Non-binary: 36*	• 18-24: 72 • 25-34: 120 • 34-44: 124 • 45-54: 52 • 55+: 24	• Under 25K: 48 • 25K-50K: 84 • 50,001 – 75K: 48 • 75,001 – 100K: 76 • Over 100K: 136 • Prefer not to answer: 8	• Death of Loved One: 288 • HC/LC Decision-Making: 252

*Data collection varied slightly for the Asian American Report Profile from other groups, accounting for the inclusion of the Trans and Non-binary gender identities.

Rural Communities Demographic Profile (n=400)

GENDER:	AGE:	INCOME:	EXPERIENCE WITH:
• Male: 184 • Female: 216	• 25-34: 132 • 35-44: 108 • 45-54: 88 • 55+: 72	• Under 25K: 64 • 25k-50K: 88 • 50,001 – 75K: 80 • 75,001 – 100K: 76 • Over 100K: 68 • Prefer not to answer: 24	• Death of Loved One: 292 • HC/LC Decision-Making: 252

What qualifies as rural?

- Urban refers to densely developed territories that have populations of 50,000 or more.
- Rural encompasses all populations, housing, and territory **not included** within an urban area.

Key Domains for Increasing Access to Care

CONNECT enhances and improves access to care by addressing key factors that influence quality, equity, and patient-centered support.

- **Communication** – Identifying and strengthening opportunities for more effective communication, including language principles and channels.
- **Outcomes** – Prioritizing quality through the fundamental factors that influence care.
- **Network** – Building trust through reliable resources and support systems.
- **Nurture** – Promoting person-centered care and cultural humility.
- **Engagement** – Encouraging active participation from providers, patients, and caregivers.
- **Collaboration** – Fostering shared decision-making, co-created care plans, and community partnerships.
- **Transparency** – Ensuring clarity in care processes and quality measures.

By integrating these principles, CONNECT supports equitable, inclusive, and comprehensive access to care.

Communication

Lack of awareness and access to information present formidable barriers to accessing care. However, effective communication can empower people by giving them the knowledge they need to make informed decisions about hospice and at-home care.

Fundamental approaches to improved communication include diversifying educational materials to include formats that match the language, culture, and preferred media/ communication channels of patients and their caregivers.

> I would feel if you're non-Hispanic, but you spoke Spanish and could communicate, I would have some type of a bond.

Language can be a significant barrier for non-native English speakers, particularly in hospice and home care settings.

- **More than half (52%) of Hispanic respondents indicated that having hospice workers who spoke their loved one's language was essential for their comfort.**
- Similarly, language and communication are critically important to Asian Americans in this context, as many patients from this group are first-generation immigrants with varying levels of English fluency.
- These individuals often rely on home caregivers for translation assistance, further reinforcing the preference for home care over facility-based care, where language barriers might prevent them from articulating their needs effectively.

How you communicate with caregivers about hospice and home care is just as important as what you communicate. While some people prefer direct, face-to-face interactions with healthcare providers, others prefer less direct types of communication such as texting or via internet portal. Broadly, advancements in technology have introduced numerous ways to communicate and share information, however individuals living in rural areas may face challenges such as limited access to high-speed internet and inconsistent cellular phone signals, which should be considered.

> My parents were born in China, and they don't really speak English. And where we live in Florida, there is not a big Chinese population, so it's very difficult to find someone that they can converse with.

Generational differences also influence communication methods. **Younger individuals (under 45) tend to prefer asynchronous communication, such as text messaging, while older individuals (over 55) favor direct, face-to-face conversations with healthcare providers.** Overall, for first-generation older adults, the primary barrier to seeking healthcare remains language, highlighting the need for linguistically and culturally sensitive care solutions. These findings underscore the need for strategic interventions; such as culturally relevant education, expanded home hospice options, and caregiver support to ensure equitable access and high-quality outcomes.

For more information on Culturally Sensitive Communications, download our resource guide, allianceforcareathome.org/wp-content/uploads/Culturally_Sensitive_Communications.pdf

Recommendations:

- Written materials (both print and digital) should be available in a variety of languages. Even if a patient and/or their loved ones can read English, offering materials in their native language, and in a culturally appropriate way, demonstrates a commitment to honoring their culture *beyond meeting the statutory requirements*.
- Diversity of language is a key component to overall diversity. Hospice organizations should aspire to language diversity that mirror that of their patient population.
- Develop best practices and policies for the use of qualified medical interpreters within each individual organization.
- When speaking with patients and their loved ones, provide clear, concise communication points to ensure that key pieces of information are not "lost in translation."
- Upon intake, be sure to ask about communication preferences and capabilities to ensure seamless communication with patients, families, and caregivers. If needed, gather contact information for multiple contacts in the event that signal challenges exist.

Outcomes

> It's not part of our culture to put your elders in a facility, it is our responsibility to take care of our parents, grandparents. But, it is so hard to do that because I am working but no one in our family has ever put someone in a facility.

While many of the key domains of CONNECT focus on strategic approaches to increasing access to care, outcomes represent the result of those strategies: namely, high-quality, equitable care for everyone seeking hospice and/or at-home care.

A sizable group of Black **(22%)** and Hispanic **(25%)** respondents are either unaware or unsure whether hospice care can be provided in the home or a healthcare facility. This lack of awareness may contribute to disparities in hospice utilization. Additionally, Black and Hispanic respondents are significantly more likely than White respondents **(32% vs. 42% vs. 48%)** to forgo hospice care if they believe it is only available in a facility rather than at home, highlighting the importance of educating the community about their home-based care options.

Caregiving can be mentally and emotionally exhausting, as recognized by **more than three-quarters of respondents.** Nearly three out of five respondents acknowledged that, at times, they needed a break from caregiving but were unable to take one. Cultural expectations also play a significant role in caregiving decisions. Within Asian American communities, the philosophy of "taking care of one's own" is deeply ingrained. Even those who were unable to care for their parents at home expressed a sense of responsibility and believed they should have done so under different circumstances. However, perspectives on caregiving vary, as many focus group participants stated that they would not want to burden their children or grandchildren and would instead suggest using a facility for their care needs.

Recommendations:

- Caregivers should be assured of the many options available for hospice care. Hospice can be provided at the patient's residence, an inpatient facility, a nursing home, or wherever the patient calls home.
- Get to know patients' and families' expectations and fears. Assure patients and their families that hospice care can be customized to meet their individual needs.
- Implement culturally relevant community outreach to improve awareness of hospice care options, which could lead to increased enrollment and earlier access to quality end-of-life care.
- Expand access to respite care and culturally responsive services, reducing caregiver burnout and ensuring sustained, high-quality care for patients. Culturally responsive services is defined "as a process of actively developing a synergistic relationship grounded in mutuality and an intentional respect for a person's cultures."[1]

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1. Muñoz JP. Culturally responsive caring in occupational therapy. Occup Ther Int. 2007;14(4):256-80. doi: 10.1002/oti.238. PMID: 17966110.

Network

Decision-making around important home care decisions can be strongly influenced by people's personal networks. These can include family, friends, cultural communities, and spiritual organizations. The wisdom and insights of these networks should be viewed as complementary to the information provided by hospice and home care organizations themselves.

> Our place of worship is where everyone goes. That is where my parents meet other people their age and get recommendations for doctors that would work best with them. Obviously, most of them are Asian and whom they could relate to.

Cultural expectations can significantly influence hospice decision-making amongst patients and their families. Those who have not lived in the United States their entire lives may not be accustomed to having autonomy in choosing a provider, making the decision process overwhelming. Additionally, while there is general trust in local healthcare resources, **30% of respondents** lack confidence in their local hospitals to provide high-quality care, with particular concerns about rural hospital quality.

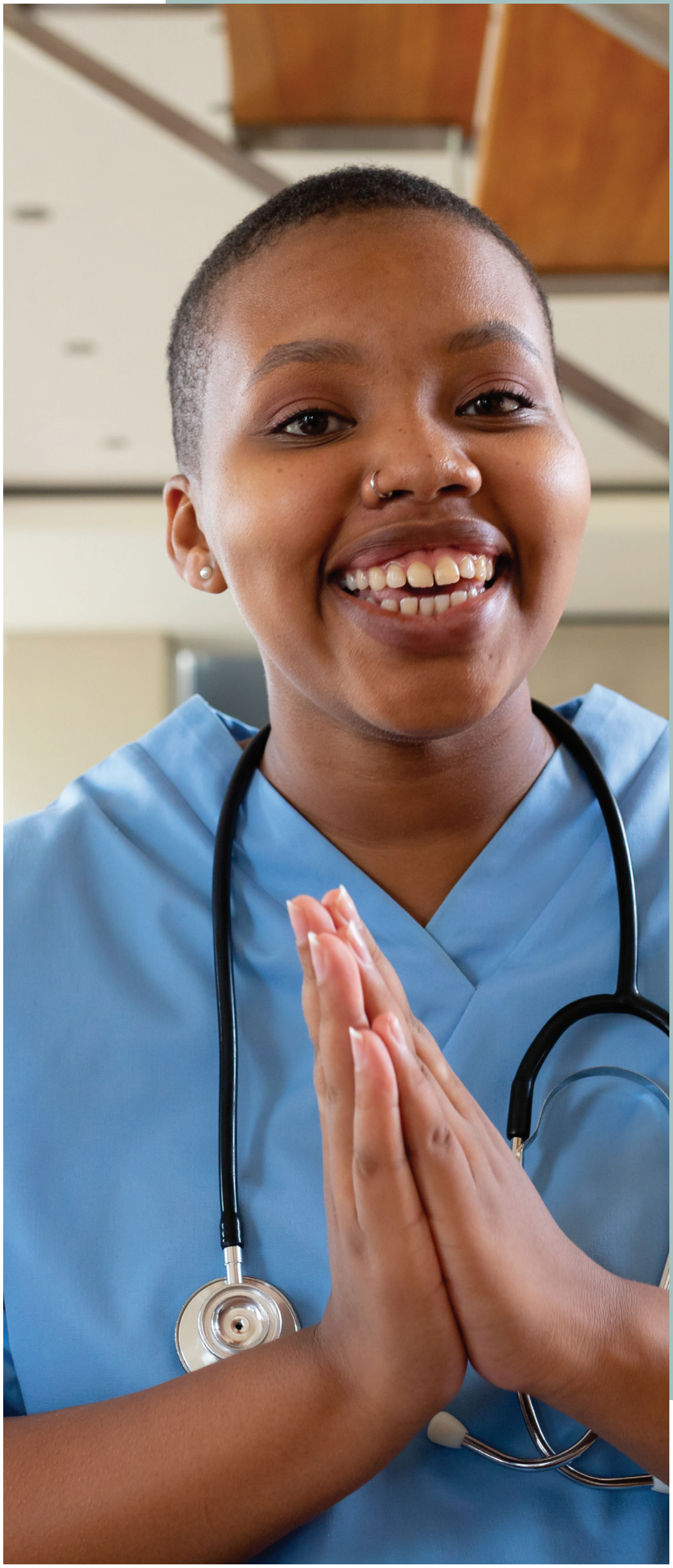
When seeking information about hospice providers, primary physicians and insurance companies serve as key stakeholders and educational sources, but **online resources are becoming increasingly influential.** Respondents emphasized the importance of being proactive in searching for information. From an information-sharing perspective, many prefer to learn about hospice through their social networks, such as churches and community groups, and rely on guidance from trusted individuals within those circles, including through social media.

Trust in recommendations varies across cultures. For example, overall Asian Americans are more likely to trust family over doctors when making hospice and end-of-life care decisions. However, preferences differ based on nationality: Chinese respondents value doctor recommendations, while Indian, Korean, and Japanese respondents prioritize family input. Filipino and Vietnamese respondents tend to trust recommendations from people in their broader community, whereas Polynesian respondents rely more on hospital staff for guidance. These cultural nuances highlight the importance of tailored communication and outreach strategies to ensure informed and supportive hospice decision-making.

Recommendations:

- A small but significant gap in trust of local rural hospitals presents an opportunity for hospice care organizations to fulfill the unmet needs of eligible patients and their caregivers.
- Recognize that Asian Americans are not monolithic in their views; they comprise many different cultures which have their own distinct views on hospice and trusted resources.

- If there are engaged family members living abroad, there may be a layered decision-making process when it comes to hospice.
- Recognizing the influence of personal networks in healthcare decisions, hospice organizations should develop tailored communication strategies that align with community-specific trust patterns. This includes leveraging faith leaders for Black and Hispanic communities, social media and community groups for rural populations, and culturally specific decision-making preferences among Asian subgroups. These efforts will lead to increased hospice enrollment and earlier access to care that aligns with patient and family values.



Nurture

The Nurture domain is built on the tenet of person-centered care that is tailored to the individual. The needs and preferences of each individual are often culturally rooted, and it's critical that care providers show an awareness of and respect for those cultural differences.

> The majority are basically underwritten by one religious organization or another. Many of my LGBTQ peers don't ascribe to religion so you're putting them in an awkward situation.

Survey findings reveal distinct preferences regarding the inclusion of a spiritual or religious component in hospice care. **Compared to White respondents, Black respondents are significantly more likely to desire a spiritual aspect in hospice services (59% vs. 50%). In contrast, the LGBTQ+ community expresses the lowest interest in incorporating spirituality or religion into hospice care, with only 39% indicating a preference,** significantly lower than other groups. Overall, the majority of Asian American caregivers value a spiritual component for both them and their loved ones, with those aged 45-54 being the most likely to prioritize it.

Beyond spiritual considerations, the top priority for respondents is ensuring that hospice care is available wherever the patient resides. Additionally, rural caregivers emphasize the importance of hospice workers providing care for their loved ones so they can continue working. This need is particularly pronounced among rural caregivers under 45 and those aged 45-55, highlighting the importance of hospice services that accommodate the demands of working caregivers.

Recommendations:

- Hospice organizations should clearly communicate their spiritual and religious care offerings, ensuring patients and families understand that chaplains provide support based on individual needs, not religious conversion.
- Providers should initiate open discussions about cultural and religious preferences before establishing care, ensuring individualized support that aligns with each patient's values.
- Hospice organizations should proactively build relationships with diverse spiritual leaders in the community to ensure culturally competent care. Collaboration with clergy should be patient-driven, reinforcing trust and respect for religious traditions.
- Caregivers are looking for flexibility in hospice care, with the ability to have care delivered at home and/or at a nearby location. Both options allow people to continue working, which is especially important to younger caregivers.
- Encourage staff music therapists to explore musical offerings that support different religions and spiritual practices.

Engagement

Ensuring patients and their loved ones are engaged, active participants in their hospice or care at home journey is key to delivering successful outcomes. When they are actively consulted and involved in key decision-making, patients feel an important sense of agency that can positively impact their care.

> A person who looks like me, when they look at my family, will be able to understand a little bit differently versus someone who doesn't have the same cultural experiences.

Key concerns were highlighted regarding hospice care across different demographic groups. **Black respondents are significantly more likely than White respondents (21% vs. 11%) to feel more comfortable with hospice workers who share the same ethnicity as their loved one,** emphasizing the importance of culturally relevant care. **LGBTQ+ respondents also express notable concerns, with nearly one-third doubting or being unsure whether hospice providers would respect their sexuality.** Many respondents indicated that they would be more inclined to trust a hospice organization if members of the LGBTQ+ community held decision-making roles, underscoring the need for visible representation in leadership to foster trust.

Rural respondents were asked about their expectations regarding hospice care, focusing on three key areas: whether hospice workers would respect and understand them as caregivers, whether a hospice team could arrive within an hour if needed, and whether hospice providers would offer non-judgmental care. **Across age groups, 27% to 42% of respondents expressed doubts about these assurances.** The most significant concerns were found among rural individuals under 45, who had the least confidence in the ability of a hospice team to respond promptly.

Cultural perspectives also shape attitudes toward end-of-life care. Asian American respondents strongly align with the philosophy of "caring for one's own," making the idea of entrusting a loved one's care to strangers feel unfamiliar or uncomfortable. While many Asian Americans feel respected by healthcare providers, one in four respondents do not believe their healthcare wishes are fully honored, highlighting an opportunity for hospice organizations to improve engagement and culturally responsive care efforts.

Recommendations:

- Encourage diversity at all levels of hospice staff and leadership to reflect the cultural backgrounds and needs of the communities served. Commit to culturally relevant care by incorporating clear, actionable examples in both internal and external communications. Provide ongoing education for staff to address the specific cultural needs and values of your community, ensuring a responsive and inclusive environment for all patients.

- Establish an inclusive environment by consistently collecting demographic information, including gender identity and preferred pronouns, and reassuring patients that they will be treated with respect. Incorporate representation in decision-making roles to further build trust within this community.
- To help foster trust, be transparent with caregivers about expected response times, especially regarding urgent situations. Clearly communicate that hospice care can be delivered wherever the patient calls home, with flexibility to include cultural preferences and needs in the care plan.
- Engage local community members or employees to share cultural traditions and values with staff, ensuring culturally sensitive care. Recognize that for many communities, the idea of institutionalizing elders may be uncomfortable, so emphasize hospice as an approach to care rather than a location.
- Be mindful that respectful treatment varies based on cultural norms and family dynamics and the unique needs of each individual. Use the teach-back method to ensure understanding and informed consent, especially for non-native speakers.

Collaboration

> We do hospice presentations wherever we can to inform the public about what it is. Sometimes that's in nursing homes and sometimes it's at the local Kiwanis Club."

When active engagement of patients and caregivers occurs, successful collaboration naturally follows. This sort of collaboration allows patients to engage in shared decision-making, along with other stakeholders, related to their care.

Community partnerships continue to be important in hospice care, but patients and loved ones tend to trust their doctors more than anyone else when it comes to being referred to a specific hospice. **Nearly half of LGBTQ+ respondents believe doctors wait too long to discuss hospice,** turning it into a crisis decision, with a similar sentiment expressed by a significant number of Hispanic respondents.

For the most part, caregivers are looking to healthcare providers and hospice organizations for education on hospice. Some caregivers view religious organizations as sources of hospice education, but this is seen more in younger (<45) individuals. When asked who respondents would trust to recommend a specific hospice organization for services, those less than 45 years old and 45-54 were more likely to trust the recommendation of someone who has used hospice in the community. Respondents age 55+ were more likely to trust the recommendation of their primary care physician.

Recommendations:

- Offer in-services to healthcare providers on how to have conversations about hospice with patients and families to dispel any misperceptions. This can help build partnerships and ensure that healthcare providers understand when the right time is to bring in a hospice team.
- One size does not fit all when it comes to teaching caregivers about end-of-life care decision-making. Be sure to offer multiple formats for learning to help meet their specific needs and preferences.
- Engage with community leaders to better understand their unique cultural perspectives on hospice care. Collaborate with these leaders to develop educational materials and outreach efforts that resonate with each community and ensure that the messaging around hospice care is culturally relevant, respectful, and effectively reaches individuals in each community.
- Care organizations have an opportunity to provide education about hospice by engaging local community sources and educational institutions (e.g. libraries, community colleges) that promote courses for people age 55+.

Transparency

> Part of meeting patients where they are includes learning about their cultural, spirituality, and traditions. We see patients who are Amish and don't have electricity or phones and patients from the Maharishi community who have their own unique traditions. We've invited them in to help us know how to respect and honor them."

To build trust and understanding of hospice care, patients and their loved ones need to feel that information is being provided in an up-front, transparent way. From discussing the Medicare hospice benefit with prospective patients to providing thorough care plan details to patients' loved ones, honest, transparent communication is essential for solidifying confidence in hospice care.

Compared to other groups, there is a greater knowledge gap regarding hospice and palliative care services among **Hispanic participants, with 67% expressing a desire to know more about the services offered.** Even when patients and caregivers are familiar with the benefits of hospice care, many are unaware of the hospice options available in their local area. **Over 40% of rural respondents were unable to name at least one hospice provider in their community.** A challenge among Asian American participants can vary based on their experiences with Western culture. While all family members want to be involved in the care of elderly parents, some have accepted "Western" thinking, while others have not. This discord highlights the importance of explaining hospice care in terms of how it can be provided at home, how decision-making remains with the family, and how cultural preferences are respected.

Compared to White respondents (52%), Black (39%) and Hispanic (41%) respondents are less likely to be aware that hospice is a benefit covered by Medicare. For rural caregivers, healthcare providers and hospice organizations are their main sources of education on hospice care, with some younger caregivers (<45) also seeking information from religious organizations.

Recommendations:

- Develop materials that explain how hospice works, the Medicare benefit, and the typical costs for those with Medicaid or private insurance. These materials should be clear and concise, using non-medical language.
- Provide ongoing education about hospice services and the dying process, particularly for older individuals and underserved communities. This should include in-person conversations with patients and families, utilizing non-medical language and addressing any questions.
- Highlight the value of hospice care, emphasizing that it is an at-home option covered by Medicare and other insurance plans. This should be explained clearly through various materials, including websites, printed collateral, and online resources like YouTube or social media.

Conclusion

Applying the CONNECT framework empowers hospice and palliative care organizations to effectively address disparities in hospice care access and quality among diverse communities. This report provides actionable insights and strategies to enhance communication, build trust through reliable networks, and promote person-centered care with cultural humility. Healthcare professionals are encouraged to implement these principles to foster active engagement, collaboration, and transparency within their practices. By doing so, they can contribute to developing equitable, inclusive, and comprehensive hospice care services that meet the unique needs of all patients and their families.

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